#### **CURRICULUM VITAE**

#### **JAMES V. LAVERY**

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## **CURRENT POSITION**

Bioethicist, 2000 --

Fogarty International Center, and

Department of Clinical Bioethics, Warren Magnuson Clinical Center, National Institutes of Health, Bethesda, Maryland, U.S.A.

## **EDUCATION**

**Ph.D.** (Medical Science/Bioethics) - 1995 - 1999 Institute of Medical Science/Centre for Bioethics, University of Toronto

**M.Sc.** (Medical Science/Bioethics) - 1991-1994 Institute of Medical Science/Centre for Bioethics, University of Toronto

B.Sc. (Biology) - McMaster University 1987-1989

Honours B.A. (Psychology) - University of Western Ontario 1980-1985

## **POSTDOCTORAL TRAINING**

**Post-Doctoral Research Fellow** (Applied Ethics and Health Policy), 1999 - 2001 Queen's Health Policy Research Unit, Queen's University, Kingston, Ontario Funded jointly by the Social Sciences and Humanities Research Council and the Canadian Foundation for Health Services Research.

#### OTHER AND PREVIOUS ACADEMIC POSITIONS

**Adjunct Assistant Professor**, 1999 - 2000 Department of Community Health and Epidemiology Queen's University, Kingston, Ontario, Canada

Research Associate, 1998 - 1999 Department of Community Health and Epidemiology Queen's University, Kingston, Ontario

## **CURRENT BOARDS AND OTHER POSITIONS**

**Chair,** Department of Health and Human Services, Working Group on Equivalent Protections (March, 2002 -- ).

## PAST BOARDS AND OTHER POSITIONS

**Chair,** NIH Working Group for response to the Council of International Organizations of Medical Sciences (CIOMS) Draft Guidelines (May 2001-July 2001).

**Member**, NIH Working Group for response to the National Bioethics Advisory Commission's International Report , October 2000 – January 2001

**Member**, U.S. Delegation, U.S. – China Science Policy Forum, National Institutes of Health, Bethesda, MD, December 4,5, 2000.

**Member**, U.S. Delegation, U.S. – India Science Policy Forum, New Delhi, India, October 18-20, 2000.

**Grants Panelist,** National Health Research and Development Program, Canadian Strategy on HIV/AIDS Community-based Research Program, 2000-01 Term [Declined due to NIH Appointment]

Canadian National Stroke Registry Ethics Committee, August 1999 – July 2000

Research Ethics Board Member, Queen's University. July 1999 – July 2000

**Member,** Kingston General Hospital Working Group on Withholding and Withdrawing Life Support, March 1999 – July 2000.

**Executive Director** (Jan 1998 - June 1998) The Community Research Initiative of Toronto

**Chair,** Ontario Advisory Committee on HIV/AIDS, Working Group on Euthanasia and Assisted Suicide, April 1997 - Present.

**Member**, Board of Directors, Community Research Initiative of Toronto, June 1997 - December 1997.

Research Associate (Dec 1997-March 31, 1998) Health Policy Research Unit, Queen's University, Kingston, Ontario

Administrative Coordinator - (July 1994 - Dec 1997)

The HIV Ontario Observational Database, Sunnybrook Health Science Centre.

**Research Ethics Board Member,** Sunnybrook Health Science Centre. May 1994 - December 1996.

Institute for Clinical Evaluative Sciences (ICES) Research Ethics Committee Member, Sunnybrook Health Science Centre Research Ethics Board Sub-Committee. January 1995 - December 1996.

**Ethics Committee Member**, Sunnybrook Health Science Centre. 1992-93.

## **AWARDS AND DISTINCTIONS**

Ontario Ministry of Health Career Scientist Award, 2000-2005. [Declined for NIH Appointment]

**Third Prize,** University of Toronto, Department of Medicine Annual Research Competition, 1999.

Social Science and Humanities Research Council of Canada, Doctoral Fellowship, 1996-1998.

University of Toronto Connaught Scholarship, Doctoral Research, 1995-1997.

**1st Prize,** Médecins Sans Frontières/Doctors Without Borders Holland, 10th Anniversary Photography Competition, 1995.

**University of Toronto Open Fellowship** 1991-1992

Summer Research Scholarship Centre for Bioethics, University of Toronto - 1991

Second Prize DuPont Essay Contest, University of Toronto - 1991

### **TEACHING EXPERIENCE**

#### "The Use of Stored Tissue in Research"

Faculty, NIH Clinical Center Department of Clinical Bioethics Short Course: Ethical and Regulatory Aspects of Human Subjects Research

Seoul, Korea, June 19, 2002 Entebbe, Uganda, March 27, 2002 Accra, Ghana, March 19, 2002

## "Coordinator, Bioethics in the Undergraduate Curriculum"

Queen's University Medical School, 1999-2000.

#### "Health Care Ethics for Medical Students--Phase 1A"

Queen's University Medical School, First Year Bioethics module, Fall 1997.

#### "Euthanasia and Assisted Suicide"

University of Toronto Medical School, Boyd Academy, third year ethics seminar, Feb 6, 1997.

## "Ethical Issues in Research Involving Human Subjects"

University of Toronto, Mount Sinai Hospital, Emergency Medicine Residents, May 28, 1996.

### "Informed Consent"

University of Torohto Medical School, Boyd Academy, third year ethics seminar, May 9, 1996.

## "Breaking Bad News to Patients, Standardized Patient Sessions - Part 2"

University of Toronto Medical School, Boyd Academy, 4th year clinical clerks, April 24, 1996.

## "Breaking Bad News to Patients, Standardized Patient Sessions - Part 1"

University of Toronto Medical School, Boyd Academy, 4th year clinical clerks, April 17, 1996.

## "Truth-Telling"

University of Toronto Medical School, Boyd Academy, second year ethics seminar, Feb 6, 1996.

### "Truth-Telling"

University of Toronto Medical School, Boyd Academy, third year ethics seminar, May 2nd, 1995.

## "Truth-Telling"

Multi-Disciplinary Ethics Rounds, Boyd Academy, Sunnybrook Health Science Centre, January 20th, 1995.

#### "AIDS and Ethics"

University of Toronto Medical School, second year ethics seminar, November 24th, 1994.

#### "Informed Consent"

University of Toronto Medical School, third year ethics seminar, October 5th, 1994.

#### "Ethics and Informed Consent"

JCL 1406, Methods for Clinical Investigation, University of Toronto/The Toronto Hospital (General Division) Residency Program in Clinical Biochemistry, Guest Lecture, January 27th, 1994.

## "Use of Life-Sustaining Treatments - Part 2"

University of Toronto Medical School, third year ethics seminar, January 24th, 1994.

## "Use of Life-Sustaining Treatments - Part 1"

University of Toronto Medical School, third year ethics seminar, January 17th, 1994.

#### "Clinical Issues in Informed Consent - Part 2"

University of Toronto Medical School, third year ethics seminar, January 12th, 1994.

#### "Clinical Issues in Informed Consent - Part 1"

University of Toronto Medical School, third year ethics seminar, January 5th, 1994.

## "Substantive Aspects of Research Ethics Review."

University of Toronto, Institute of Medical Science Graduate Course (MSC 1051 F - Research Bioethics) Guest Lecture, October 13th, 1993.

## "Questioning the Rationale for Genetic Screening"

University of Toronto fourth year undergraduate microbiology guest lecture, April 1st, 1993.

#### "Patient Demands for Futile Treatments"

University of Toronto Medical School, third year ethics seminar, January 25th, 1993.

## "Foregoing Life-Sustaining Treatment"

University of Toronto Medical School, 3rd year ethics seminar, Jan18/93

#### **PUBLICATIONS**

#### **BOOK CHAPTERS**

Lavery JV, Dickens BM, Boyle JM, and Singer PA. Euthanasia and Assisted Suicide. In: Singer PA, editor. Bioethics at the Bedside: A Clinician's Guide. Ottawa: Canadian Medical Association, 1999. p. 99-106.

#### JOURNAL ARTICLES

Robertson D, Bedell R, Lavery JV, Upshur REG. What evidence do we need to justify humanitarian medical aid? *The Lancet* 2002; 360: 330-333.

Lavery JV, Boyle J, Dickens BM, Maclean H, Singer PA. Why do people desire euthanasia

and assisted suicide? The Lancet 2001; 358 (9279): 362-367.

Heyland DK, Lavery JV, Tranmer JE, Shortt SED, Taylor SJ for the Queen's/KGH End of Life Research Working Group. Dying in Canada: Is it an institutionalized technologically supported experience? *The Journal of Palliative Care* 2000; 16 (Suppl): S10-S16.

Heyland DK, Lavery JV, Tranmer JE, Shortt SED, Taylor SJ. The epidemiology of dying in Ontario: A starting place for reform. *Annals of the Royal College of Physicians and Surgeons of Canada* 2000; 33 (6): 356-361.

Shortt SED, Lavery JV. End of life issues: The policy issues that won't die. *The Journal of Health Services Research and Policy* 1999; 4(4): 230-235.

Singer PA., Martin DK, Lavery JV, Thiel EC, Kelner M, Mendelsshon DC. Reconceptualizing Advance Care Planning from the Patient's Perspective. *Archives of General Internal Medicine* 1998; 158: 879-884.

Lavery JV, Singer PA. The "Supremes" decide on assisted suicide: what should a doctor do? (Editorial) *Canadian Medical Association Journal* August 15, 1997; 157: 405-6.

Lavery JV, Dickens BM, Boyle JM, and Singer PA. Bioethics for Clinicians: Euthanasia and Assisted Suicide. *Canadian Medical Association Journal* May 15,1997; 156(10): 1405-1408.

Meslin EM, Sutherland HJ, Lavery JV, and Till JE. Principlism and the Ethical Appraisal of Clinical Trials. *Bioethics* October 1995; 9(5): 399-418.

Meslin EM, Lavery JV, Sutherland HJ, and Till JE. Judging The Ethical Merit Of Clinical Trials: What Criteria Do Research Ethics Board Members Use? *IRB: A Review of Human Subjects Research* 1994. May-June; 6-10.

Rasooly I, Lavery JV, Urowitz S, Choudhry S, Seeman N, Meslin EM, Lowy FH Singer PA.. Hospital Policies on Life-Sustaining Treatments and Advance Directives in Canada. *Canadian Medical Association Journal* 1994; 150 (8): 1265-1270.

#### PUBLISHED ABSTRACTS

Heyland DK, Lavery JV, Tranmer JE, Shortt SED, Taylor SJ for the Queen's/KGH End of Life Research Working Group. Dying in Canada: Is it an institutionalized technologically supported experience? *Clin Invest Med* 1999.

Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner M, Mendelsshon DC. Advance Directives in Dialysis. *Journal of General Internal Medicine* 1995: 10(Suppl), 118A.

Lavery JV and Singer PA. The Use of Treatment Futility in Canadian Hospital Policies

Regarding the Use of Life-Sustaining Treatment. *Clinical and Investigative Medicine* 1993; Supplement to Vol. 16(4): B13.

#### TECHNICAL REPORTS

Shortt SED, MacDonald K, Lavery JV, Keresztes C. Accountability Frameworks in Canadian Health Care. Ottawa: Health Canada, 1999.

Lavery JV, Appleby B, Bowman K for the Queen's University/Kingston General Hospital End of Life Research Working Group. A Synthesis of Palliative Care Research. Ottawa: Palliative Care Foundation of Canada, 1999.

Lavery JV, Shortt SED. The desire for death in terminal illness: a synthesis of evidence. Ottawa: Health Canada, 1998.

Lavery JV. A legal and ethical framework for the use of personal information in an integrated information infrastructure in HIV/AIDS care. Ontario HIV Treatment Network, 1998.

#### **BOOK REVIEWS**

<u>Seeking Fair Treatment: From the AIDS Epidemic to National Health Care Reform,</u> by Norman Daniels. For: *Annals of the Royal College of Physicians and Surgeons of Canada* 1996; 29(8): 493.

#### COMMISSIONS

Building Capacity for Cultures of Ethical Conduct in International Collaborative Research. Invited Background Paper to the *World Health Organization Commission on Macroeconomics and Health, Working Group 2: Global Public Goods for Health*, Geneva <a href="http://www.cmhealth.org/docs/wg2">http://www.cmhealth.org/docs/wg2</a> paper5.pdf

In Vitro Fertilization: An Exploration of the "Is" - "Ought" Gap. Submission to the *Royal Commission on New Reproductive Technologies*, Ottawa, Canada, 1992.

## **CONFERENCE PRESENTATIONS AND SPECIAL LECTURES**

"Emerging challenges in international research ethics: Guidance for U.S. IRBs" Public Responsibility in Medicine and Research, Annual Meeting, San Diego, California, Nov 19, 2002.

## "The Ethics of Research with Stored Biological Samples"

American Society for Clinical Oncology, Annual Meeting, Orlando, Florida, May 19, 2002.

# "Building a Culture of Ethical Conduct in Research From the Ground Up" (Keynote Speaker)

Society for Research Administrators (U.S.) Annual Meeting, Stamford Connecticut, May 6, 2002.

# "Measuring the Culture of Ethical Conduct in Research: Challenges and Opportunities"

Queen's University, Department of Cummunity Health and Epidemiology, Kingston, Ontario, April 26, 2002.

# "Measuring the Culture of Ethical Conduct in Research: Challenges and Opportunities"

St. Michael's Hospital, Toronto, April 25, 2002.

# "Individual Benefit vs. Value to the Community: A Critique of 10 U.S.C. 980" (Keynote Speaker)

Uniformed Services University of the Health Sciences and National Naval Research Center, Bethesda, MD, January 30, 2002.

#### "International Research Ethics at NIH"

Strategic Initiative for the Development of Ethics Review Capacity (SIDCER) meeting, Bethesda, MD, December 5, 2001.

# "Is the Declaration of Helsinki Truly Applicable in the Developing World?" Public Responsibility in Medicine & Research, Boston MA, December 4, 2001.

"Toward a Culture of Ethical Conduct in International Collaborative Research" Joint Centre for Bioethics, University of Toronto, November 21, 2001.

# "Protecting Communities in International Collaborative Research" (Keynote Speaker)

Surgeon General's Human Subjects Review Board Conference on International Research Ethics, Frederick MD, November 20, 2001.

"Towards Progress in the Ethics of International Collaborative Research" (Organizer and Chair)

American Society for Tropical Medicine and Hygiene Annual Meeting, Atlanta, Nov 14, 2001.

"Towards a Culture of Ethical Conduct in International Collaborative Research" University of Illinois at Chicago, Chicago, Sept 11, 2001

## "Measuring the Performance of Research Ethics Systems"

World Health Organization Commission on Macroeconomics and Health, Meeting of Working Group 2: Global Public Goods for Health, Bethesda, July 19, 2001.

## "Emerging Challenges in International Research Ethics"

National Institute of Dental and Craniofacial Research Satellite Symposium, International Association of Dental Research, Chiba, Japan, June 29, 2001.

## "Challenges in Training and Education in International Research Ethics" (workshop facilitator)

Public Responsibility in Medicine & Research (PRIM&R) conference "Promoting the Responsible Conduct of Research: Policies, Challenges, and Opportunities" in Arlington, VA, May 18, 2001

## "Persistent Challenges in International Research Ethics"

Part of a four member panel at the NIH Staff Training for Extramural Programs (STEP) Forum: "Clinical Trials on Trial" in Bethesda, MD, May 17, 2001

## "Implications of emerging guidelines in international research ethics for vaccine research"

Part of a three member panel on research ethics at the National Foundation for Infectious Diseases conference on Vaccine Research in Alexandria, VA, April 23, 2001

## "Symposium on ethical issues in international collaborative research" (organizer and chair)

National Institute of Child Health and Human Development Consultation Meeting on Maternal and Child HIV/AIDS Treatment in Africa in Gaborone, Botswana, March 26, 2001

#### "International Research Ethics"

American Academy for the Advancement of Science short-course on Research Ethics in Washington, D.C., March 18, 2001

## "Update on International Research Ethics"

Presentation/consultation for the Global Health Committee of the Infectious Disease Society of America, Washington, D.C., January 30, 2001.

## "Emerging Issues in International Research Ethics"

Presentation/consultation for the Board on Global Health, Institute of Medicine, Washington, D.C., November 16, 2000.

#### "Case Studies in Bioethics Education"

Minorities in Research Training Program, Bioethics Conference, Fogarty International Center, National Institutes of Health, Bethesda, Maryland, September 13, 2000.

## "Why do people desire Euthanasia and Assisted Suicide?"

Canadian Bioethics Society Annual Conference, Edmonton, Alberta, October 30, 1999.

#### "Euthanasia and Assisted Suicide in HIV/AIDS"

HIV Health Evaluation Unit, Sunnybrook and Women's College Health Sciences Centre, Toronto, Ontario, Research Seminars, September 22, 1999.

"Losing Yourself to AIDS: The Meaning of Euthanasia and Assisted Suicide" Department of Family Medicine, Queen's University, Kingston, Ontario, Grand Rounds, August 17, 1999.

## "North of Kevorkian: Public Policy Challenges Re: Euthanasia and Assisted Suicide in Canada"

8<sup>th</sup> Annual Canadian Seminar, Columbia-Greene College, SUNY, Hudson, New York, April 29, 1999.

"Disclosure of HIV Status Following the Supreme Court's Decision in *Cuerrier*" Panelist, 'Opening Doors' Regional Conference, Gananoque, Ontario, April 16, 1999.

# "Euthanasia, Assisted Suicide and the Desire for Death in Terminal Illness" Mt. Sinai Hospital, Interdepartmental Division of Oncology, University of Toronto and the

Palliative Care Council of Toronto, Palliative Care Grand Rounds. Mt. Sinai Hospital, February 8, 1999.

# "Just Access to Health Care for People with HIV/AIDS in Canada: Who are We Kidding?"

Queen's University Faculty of Medicine AIDS Symposium, April 1, 1998.

### "From Costs to Values: Resource Allocation in HIV/AIDS"

University of Toronto, Office of Research Services "Community, Research, Ethics and Culture" Series, Faculty of Law, University of Toronto, January 27, 1998

"Euthanasia and Assisted Suicide: Challenges for the End of the Millenium" Later Life Learning Lectures, Innis College, University of Toronto, January 19, 1998.

"Research in Euthanasia and Assisted Suicide" (Panelist)

Canadian AIDS Society, Canadian HIV/AIDS Skill Building Symposium, Toronto, January 16, 1998.

## "A Theory of Decision Making Regarding Euthanasia and Assisted Suicide in HIV/AIDS"

Clinical Epidemiology Rounds, The Toronto Hospital, November 17, 1997.

### "Euthanasia and Assisted Suicide in HIV/AIDS"

Canadian Bioethics Society Annual Meeting, Halifax, October 18, 1997.

## "Ethical Issues in HIV Clinical Trials" (Panelist)

Canadian Association for HIV/AIDS Research, Ottawa, May 25, 1997.

## "Who Should Get Care? Allocation of Limited Resources" (Workshop leader)

Exploring Ethics in the Community: A Day of Discussion, Emmanuel College, University of Toronto, April 22, 1997.

#### "Ethical Issues in Palliative Care"

Regional Workshop for Hospice Workers, Metro Community Church , Toronto, February 27, 1997.

## "Workshop on Advance Care Planning" (Workshop facilitator)

Canadian Bioethics Society Annual Meeting, Montreal, October 18, 1996

#### "An Introduction to Qualitative Research".

American Society for Medical Decision annual conference, Toronto, October 13, 1996.

#### "Euthanasia and Assisted Suicide"

Mississauga Mayor's Youth Advisory Council Conference, Mississauga, October 4, 1996.

## "Lessons in the Development of the HIV Ontario Observational Database"

XI International Conference on AIDS, Vancouver, B.C., July 8, 1996.

## "Basic Concepts in Qualitative and Interdisciplinary Research"

University of Toronto, Institute of Medical Science Scientific Day, Bioethics Plenary Session (4 speakers), May 3rd, 1996.

## "Ethical Issues in Pharmacy"

The Ontario Pharmacists Association Annual Conference, Richmond Hill, Ontario, April 27, 1996.

## "Balancing Career and Family"

University of Toronto, Institute of Medical Science Career Day, Panelist (3 speakers), April 19th, 1996.

## "The Role of Pharmacists in Euthanasia and Assisted Suicide"

Canadian Association of Pharmacy Students and Interns, Faculty of Pharmacy, University of Toronto, March 20, 1996.

## "Ethical and Legal Issues in the Development of a Provincial HIV/AIDS Database in Ontario."

7th Annual Canadian Bioethics Society Conference "Health Care Ethics in a Multicultural Society, Vancouver, B.C., November 23-25, 1995.

## "Contextual Ethics: The Ethics of Care versus Principle-Based Ethics"

Telemedicine Canada. Ethical Problems in Clinical Practice Series, October 4, 1995.

## "The HIV Ontario Observational Database and Primary Care Research"

The Waterloo Region Community Health Department AIDS/STD Program and The AIDS Committee of Cambridge, Kitchener, Waterloo and area "AIDS and the Family Practice" Workshop, Kitchener, September 27th, 1995.

"Ethical Issues in the Development of the HIV Ontario Observational Database" University of Toronto Centre for Bioethics Research Seminar, December 14th, 1994.

#### "Ethical Issues in HIV/AIDS Clinical Research"

Pharmaceutical Manufacturers Association of Canada, Toronto, October 12th, 1994.

#### "The Pros and Cons of Euthanasia"

Bernard Batel Centre for Creative Living, Toronto, September 29th, 1994.

#### "Euthanasia: Pro and Con"

The Jane Hawtin Show, CFRB Radio, Toronto, August 30th, 1994

"The Use of Futility in Canadian Hopsital Policies on Life-Sustaining Treatment." University of Toronto Centre for Bioethics Research Seminar, October 6th, 1993.

# "The Use of Treatment Futility in Canadian Hospital Policies Regarding The Use of Life-Sustaining Treatment."

The Royal College of Physicians and Surgeons of Canada Annual Conference, Vancouver, B.C., September 11th, 1993.

## "Humanitarian Aid to Refugees: The Right to Intervene."

The Toronto Hospital, General Division, Medical Grand Rounds, June 3rd, 1993.

"Criteria for Assessing the Ethical Acceptability of Research Involving Human Subjects: A Comparison of Reports by Research Ethics Board Members with Published Guidelines."

University of Toronto Centre for Bioethics Research Seminars, April 19th, 1993.

## "An Ethical Analysis of Human Gene Therapy"

University of Toronto Human Genetics Seminar Series, Mar 2nd, 1993.

## "Dignity in the Clinical Setting"

American Society for Health and Human Values Conference, Memphis, Tennessee November 22nd, 1992.

## "Research Ethics Board Members' Reported Criteria for Evaluating the Ethics of Research Involving Human Subjects."

University of Toronto Centre for Bioethics Research Seminars, Nov. 16th, 1992.

# "A Needs Based Ethic for Access to Health Care Services and its Implications for Duties Beyond National Boundaries."

Canadian Bioethics Society Conference, Toronto, October 31st, 1992.

## "Euthanasia and Refusal of Life-Sustaining Treatment"

Taylor Place Community Centre, Don Mills Ontario, March 16th, 1992

#### "Advance Directives"

*Especially for Women*, Kitchener Zonta International Club Annual Conference, Kitchener Ontario, March 1st, 1992.

## "Dignity and Medical Decision Making"

Canadian Bioethics Society Conference, Hamilton, November 23rd, 1991.

#### "Applied Ethics in Science"

Workshop on Ethical Considerations in Scholarship and Science, University of Toronto, November 9th, 1991.